

The unmet needs of family caregivers in the management of childhood community-acquired pneumonia in Indonesia: a qualitative study

Nyimas Heny Purwati, Yeni Rustina, Bambang Supriyatno

Abstract

Background Childhood community-acquired pneumonia (CAP) is one of the leading causes of morbidity and mortality in children under five years of age.

Objective To explore the unmet needs of family caregivers of children with community-acquired pneumonia.

Methods A qualitative study using in-depth interviews was conducted at one referral hospital located in Jakarta, Indonesia. Convenience sampling was used to select participants. Data were analyzed using qualitative content analysis.

Results Ten family caregivers participated in our study. The results of this research are shown in five main themes: (1) the burden of persistent symptoms; (2) exposure to cigarette smoke at home; (3) home remedies as initial treatment; (4) fulfilling the children's nutritional needs; and (5) health promotion needs. The care of children with CAP involves more than antibiotic treatment and vaccines.

Conclusion This study found several unmet needs of family caregivers in caring for children with CAP, particularly pertaining to health promotion and the fulfillment of nutritional needs. [Paediatr Indones. 2022;62:32-6 ; DOI: 10.14238/pi62.1.2022.32-6].

Keywords: community-acquired pneumonia; caregivers; unmet needs; qualitative study

Community-acquired pneumonia (CAP) is defined by the *World Health Organization* (WHO) as a form of acute respiratory infection that affects the lungs and is generally spread by direct contact with infected people. In Indonesia, pneumonia is one of the leading causes of morbidity and mortality, accounting for 15.5% of all causes of death among children under five years of age in 2017. In 2017, the incidence of pneumonia

in Indonesia was 20.54 per 1,000; the mortality rate increased from 0.22% in 2016 to 0.34% in 2017.¹

The management of CAP chiefly consists of antibiotic treatment and prevention.² The WHO recommends immunization with pneumococcal conjugate vaccines for all children, breastfeeding, and reducing risk factors, such as pollutant and tobacco smoke exposure.³ However, in low- and middle-income countries like Indonesia, a lack of resources leads to inadequate organized care of children with CAP.^{4,5} Along with the increase in CAP cases, the rate of longer term sequelae after childhood pneumonia such as obstructive lung disease, chronic bronchitis, asthma, and abnormal pulmonary function, has also increased. Pneumonia early in life might impair lung function long after the patient is no longer infectious.³

Due to children's inability to take care of themselves, families are the cornerstones of effective CAP care in children. The main problems with caregiving are stress, conflicts in the family environment, and economic

From the Department of Nursing, Universitas Muhammadiyah Jakarta, Indonesia (NHP, YR) and the Department of Child Health, Universitas Indonesia Faculty of Medicine (BS)

Corresponding author: Nyimas Heny Purwati. Department of Nursing, Universitas Muhammadiyah Jakarta, Indonesia. Jl. Cempaka Putih Tengah I No.1, RT 11/RW 5, Cempaka Putih Timur, Jakarta Pusat 10510. Email: nyimas_hp@yahoo.com.

Submitted May 5, 2021. Accepted January 21, 2022.

burden.⁴ In addition, lack of appropriate coping skills and poor social and familial support in dealing with the child with CAP contribute to the problem.⁵ A systematic review in another age group showed that the caregiver's role was significantly associated with readmission in CAP patients.⁶ Addressing the needs of the family caregiver is very important to make sure the child receives appropriate care. However, the needs of the family caregiver in childhood CAP are poorly understood. Due to the focus of health systems on symptomatic treatment of the sick children and the lack of appropriate communication with their families, caregivers usually receive insufficient attention and are left unsupported. To our knowledge, no qualitative or quantitative study has explored the needs of family caregivers of children with CAP. Therefore, the aim of this study was to explore the unmet needs of family caregivers of children with CAP in Indonesia for the purpose of providing better support.

Methods

This pilot study with a qualitative design using in-depth interviews was conducted to explore the unmet needs of family caregivers of children with CAP in Jakarta. Inductive qualitative research guidelines were used in this study.⁷

This study was conducted at Koja Public General Hospital located in Jakarta, Indonesia. The population was mothers with children diagnosed with CAP. Convenience sampling was employed. Interviews were conducted until data saturation, i.e. the point when no new information is discovered.⁷ Sample size was determined according to the saturation of the data, with at least 5 to 15 participants.⁷

This study had been approved by the Ethics Committee, Koja Public General Hospital, before data collection. Participants were approached individually to set up a convenient time and place to conduct interviews. Written informed consent and permission to record the conversation were obtained before the interview. In-depth interviews were conducted face-to-face in a quiet room to ensure privacy and confidentiality. The average duration for each interview was approximately about 30-40 minutes. The audio recording was transcribed verbatim and independently coded by the researchers. Interview guidelines were

developed through literature review from a previous study.⁶

The transcripts were analyzed using four steps, namely: (1) processing and preparing data by scanning material, typing field data, or sorting and compiling data into different types depending on information sources; (2) reading all the data to build a general sense of the information obtained and reflecting on its meaning as a whole; (3) analyzing the data in more detail by coding the data; and (4) applying coding processes to describe settings, categories, and themes.⁸

Results

A total of 10 family caregivers participated in this study, ranging in age from 24 to 31 years. Most participants were housewives and had completed senior high school. Five themes emerged: (1) burden of persistent symptoms; (2) family members smoking at home; (3) the use of herbal medicine for initial treatment; (4) nutritional needs; and (5) health promotion needs.

Nine participants reported that the most common symptoms of CAP in the children they cared for were fever, cough, cold, difficulty removing phlegm, fatigue, hoarseness, breathlessness, and sweating.

"The symptoms are fever, cough, runny nose, and phlegm. The child cannot get the phlegm out, perhaps because he sleeps a lot due to the cough." (P1)

"The symptoms are fever, cough, and runny nose. He suddenly gets weak, has a lot of phlegm, and is unable to get it out." (P2)

"Cough, runny nose, fever and sweating, and hoarse voice." (P6)

One participant reported that in addition to experiencing coughing and shortness of breath, other complaints of the child included easy fatigability, as illustrated in the following comment:

"He seemed to be holding his breath yesterday... until he coughed, his veins seemed to tighten when he did." (P7)

Maintaining clean air quality in the home was deemed of high importance by participants. Participants attempted to improve air quality by routinely cleaning house and opening windows, even though occasionally there was still exposure to cigarette smoke inside and outside the house. Participants reported that it was difficult to maintain good air quality, especially with

regards to avoiding cigarette smoke.

"I clean my house every day, which is sometimes covered in dust. My husband smokes, sometimes near his son, and sometimes outside. On hot days, we have to open the windows." (P2)

"Every day the house is thoroughly cleaned, but my husband and many neighbors smoke. When the windows are open the smoke blows into the house." (P8)

One participant said that they had not taken precautions because the family was still exposed to cigarette smoke despite keeping the windows closed.

"My husband smokes. At times he smokes near his son if he does not want to go outside, but he claims it is OK. We sometimes open the windows, but the house becomes dusty due to the location near public roads. There is a lot of dust if the house is not cleaned daily." (P1)

One participant said that she sometimes opens the windows and does not allow people to smoke in her house in order to limit her child's coughing.

"If no one smokes at home, sometimes the windows of the house are opened and the windows are cleaned every day." (P7)

Caregiver interviews revealed that symptoms such as cough were managed by massage, medicine, herbal treatment with saga leaves, or visiting a clinic or health care center.

"My father-in-law recommends massage with hot water and eucalyptus, but my son did not like it, so we massaged his body with onions." (P1)

"I treated the fever with paracetamol and cold compresses, but if the fever did not decrease then we went to the clinic." (P3)

"I immediately took my child to the health center...or gave an over-the-counter medicine." (P4)

Nine participants said that their children experienced appetite loss and ate little.

"My child found it difficult to eat. He could not even finish his porridge which he usually enjoys. It took him a long time to eat. I also gave him vegetables and fried tempeh, but he has no appetite while sick." (P2)

One participant revealed that his child ate meals as usual.

"He eats normal food three times a day. He likes to eat tempeh or fried chicken, but not vegetables. I just let it go, to avoid tears. I am happy he still has an appetite." (P1)

The family caregivers reported that doctors only informed them that their child had a lung infection and that the medicine must be taken until the treatment course was completed. The healthcare professional did not explain the disease, how it is transmitted, what should be done at home, how to manage it, or how to prevent it.

"The doctors or nurses did not explain it completely. They just said she had a cough and cold. The medicine should be taken to completion." (P3)

"I was not given a complete explanation. All they said was that my child had an infection and had to be treated." (P5)

Discussion

The symptoms most frequently reported were cough, fever, and breathlessness. Symptoms of CAP are similar to those of the common cold. Thus, family caregivers need to have sufficient knowledge to recognize symptoms; this knowledge affects health-seeking behavior. A previous study highlighted that parents often perceive symptoms as common and harmless, and therefore treatable at home. Parents would only bring their children to the hospital when symptoms worsened.⁹ Ferdous et al reported that recognizing CAP symptoms is critical to preventing death from pneumonia in childhood.¹⁰ Previous studies showed that the lack of maternal knowledge regarding signs and symptoms as well as severity of disease leads to ineffective treatment due to delayed or unnecessary treatment.⁹ Therefore, it is essential that health care professionals educate mothers and caregivers about the symptoms of pneumonia and how to differentiate it from the common cold.

Our findings highlight that, despite the importance of a clean and properly ventilated house to lung health, caregivers could not control environmental exposure to cigarette smoke. Hartati et al showed that toddlers who lived in homes without proper air ventilation had 2.5 times the risk of pneumonia compared to those with proper air ventilation.¹¹ We also found that fathers commonly smoked inside the home. Parental smoking is a risk factor for increased vulnerability to pneumonia in children. Continuous exposure to cigarette smoke may increase the risk and recurrence of pneumonia.¹² Effective strategies are needed to prevent childhood

pneumonia associated with exposure to air pollutants, including cigarette smoke.

Home care of children with CAP is also very important. Most participants in our study explained that they treated symptoms with simple home remedies, such as with a combination of herbs, including saga leaves, or onion massage. Research conducted in Africa identified beliefs, cultures, religions, habits, perceived severity of illness, and previous experience with health workers to be significant factors that influenced the decisions of mothers and caregivers to seek treatment.¹³⁻¹⁵ The ability of caregivers to provide care is an important determinant in avoiding deterioration of symptoms in children.^{16,17} In their discharge planning, healthcare professionals need to provide comprehensive information on the care of a child with CAP at home, the scheduling of follow-up appointments, and the prevention of recurrence.

Participants reported that patients were generally fussy, lost their appetite, and did not want to play. Decreased appetite leading to food refusal is often the initial sign of infection in children. Rejection of food means reduced intake of nutrients. The child's condition will gradually deteriorate if the infection is accompanied by vomiting, which results in further loss of nutrients. Nutritional intake during the illness greatly affects physical growth and immunity. Insufficient nutrient intake increases vulnerability to and severity of infection.¹⁸

Most participants had rarely or never heard of the term 'pneumonia' as an infectious disease of the respiratory tract and lungs, and only knew of the common cold, as experienced by many children. In the hospital, information about pneumonia was also very rarely provided to participants as well as family members. Providing information raises a person's knowledge level which ultimately influences the increase in motivation and attitude towards treatment.¹⁹ New knowledge about health encourages healthy behavior.¹

In conclusion, family caregivers of children with CAP have various unmet needs. Addressing their needs could reduce CAP treatment failure as well as the burden to the family. Since pneumonia is a potentially recurrent acute infection, ignoring the needs of caregivers may adversely affect the timely diagnosis and treatment and the prevention of future recurrences of CAP in children. Further studies are needed to address the needs of caregivers of children with CAP and the

obstacles they face in adequately caring for the children.

Conflict of Interest

None declared.

Funding Acknowledgment

The authors received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. Kementerian Kesehatan RI. Profil Kesehatan Indonesia 2017. Published online 2017. [cited 2020 May 30]. Available from: <https://www.kemkes.go.id/article/view/18042300004/data-dan-informasi-profil-kesehatan-indonesia-2017.html>.
2. Prina E, Ranzani OT, Torres A. Community-acquired pneumonia. *Lancet*. 2015;386:1097-108. DOI: 10.1016/S0140-6736(15)60733-4.
3. le Roux DM, Zar HJ. Community-acquired pneumonia in children - a changing spectrum of disease. *Pediatr Radiol*. 2017;47:1392-8. DOI: 10.1007/s00247-017-3827-8.
4. Gray D, Turkovic L, Willemsse L, Visagie A, Vanker A, Stein DJ, et al. Lung function in African infants in the Drakenstein Child Health Study. Impact of lower respiratory tract illness. *Am J Respir Crit Care Med*. 2016;195:212-20. DOI: 10.1164/rccm.201601-0188OC.
5. Tan KK, Dang DA, Kim KH, Kartasasmita C, Kim HM, Zhang XH, et al. Burden of hospitalized childhood community-acquired pneumonia: a retrospective cross-sectional study in Vietnam, Malaysia, Indonesia and the Republic of Korea. *Hum Vaccin Immunother*. 2018;14:95-105. DOI: 10.1080/21645515.2017.1375073.
6. Pahlavanzadeh S, Mousavi S, Maghsoudi J. Exploring the needs of family caregivers of children with attention deficit hyperactivity disorder: a qualitative study. *Iran J Nurs Midwifery Res*. 2018;23:149-154. DOI: 10.4103/ijnmr.IJNMR_16_17.
7. Creswell JW. *Research design pendekatan kualitatif, kuantitatif dan mixed*. Yogyakarta: Pustaka Pelajar; 2013. p.76.
8. McLeod-Sordjan R, Krajewski B, Jean-Baptiste P, Barone J, Worral P. Effectiveness of patient-caregiver dyad discharge interventions on hospital readmissions of elderly patients with community acquired pneumonia: a systematic review.

- JB Libr Syst Rev. 2011;9:437-63. DOI: 10.11124/01938924-201109140-00001.
9. Creswell JW, Poth CN. Qualitative inquiry and research design: choosing among five approaches. California: SAGE Publ; 2013. p. 11.
 10. Ferdous F, Farzana FD, Ahmed S, Das SK, Malek MA, Das J, et al. Mothers' perception and healthcare seeking behavior of pneumonia children in rural Bangladesh. ISRN Family Med. 2014;2014:690315. DOI: 10.1155/2014/690315.
 11. Hartati S, Nurhaeni N, Gayatri D. Faktor risiko terjadinya pneumonia pada anak balita. J Keperawatan Indones. 2012;15:13-20. DOI: 10.7454/jki.v15i1.42.
 12. Jones L, Hashim A, McKeever T, Cook D, Britton J, Leonardi-Bee J. Parental and household smoking and the increased risk of bronchitis, bronchiolitis and other lower respiratory infections in infancy: systematic review and meta-analysis. Respir Res. 2011;12:5. DOI: 10.1186/1465-9921-12-5.
 13. Colvin C, Smith H, Swartz A, Ahs JW, de Heer J, Opiyo N, et al. Understanding careseeking for child illness in sub-Saharan Africa: a systematic review and conceptual framework based on qualitative research of household recognition and response to child diarrhoea, pneumonia and malaria. Soc Sci Med. 2013;86:66-78. DOI: 10.1016/j.socscimed.2013.02.031
 14. Geldsetzer P, Williams T, Kirolos A, Mitchell S, Ratcliffe LA, Kohli-Lynch MK, et al. The recognition of and care seeking behaviour for childhood illness in developing countries: a systematic review. PLoS One. 2014;9:e93427. DOI: 10.1371/journal.pone.0093427
 15. Noordam A, Carvajal-Velez L, Sharkey A, Young M, Cals J. Care seeking behaviour for children with suspected pneumonia in countries in sub-Saharan Africa with high pneumonia mortality. PLoS One. 2015;10:e0117919. DOI: 10.1371/journal.pone.0117919.
 16. Bruce CS, Hoare C, Mukherjee A, Paul SB. Managing acute respiratory tract infections in children. Br J Nurs. 2017;26:602-9. DOI: 10.12968/bjon.2017.26.11.602
 17. Edmond K, Scott S, Korczak V, Ward C, Sanderson C, Theodoratou E, et al. Long term sequelae from childhood pneumonia; systematic review and meta-analysis. PLoS One. 2012;7:e31239. DOI: 10.1371/journal.pone.0031239.
 18. Pajuelo MJ, Huaynate CA, Correa M, Malpartida HM, Asayaq CR, Seminario JR, et al. Delays in seeking and receiving health care services for pneumonia in children under five in the Peruvian Amazon: a mixed-methods study on caregivers' perceptions. BMC Health Serv Res. 2018;18:149. DOI: 10.1186/s12913-018-2950-z.
 19. Paul SP, Wilkinson R, Routley C. Management of respiratory tract infections in children. Nurs Res Rev. 2014;4:135-48. DOI: 10.2147/NRR.S43033.